

FACTORS IMPACTING ON ADHERENCE TO ANTIRETROVIRAL TREATMENT AT FALSE BAY HOSPITAL

by

Nosivuyile Vanqa

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Supervisor: Dr Greg Munro

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DECLARATION

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SUMMARY

The purpose of this research was to investigate factors impacting on adherence to antiretroviral treatment on people living with HIV and to further explore challenges they come across with adherence. The primary focus of this investigation relates to the following four themes.

(i) To evaluate demographic factors such as age, gender and socio-economic factors and the influence they have or contribution to adherence, in correlation with the effects of cultural and health beliefs in this context. (ii) To establish the significance of counselling and review critical challenging issues that needs consideration. (iii) To investigate the nature of reception (negative or (positive) that patient receives in this local health facility, including the nature of perceived youth friendliness as it may act as a deterrent for confidentiality with regard to referrals. (iv) To determine perceived relationship between health care providers and patients, by patients in terms of support system, referral systems and the prevention of stigma and discrimination.

This study comprises of the literature analysis on adherence globally and in the South African context, reviewing the challenges experienced by many South Africans and people living in this country. The study was implemented at a Government's facility in a health care sector "False Bay Hospital" in the Western Cape, through one focus group and ten semi-structured interviews with patients. The findings of the study reveal that stigma and discrimination is one of the leading causes to poor adherence on antiretroviral treatment including social problems experienced by PLWA. Support and counselling programmes provided at False Bay Hospital were significant but did not necessarily help PLWA in other challenges they came across with. This study also demonstrated the importance of health education and good relationship with patience has a positive effect towards adherence and improves chances of better health.

OPSOMMING

Die doel van hierdie navorsing was om faktore te ondersoek wat 'n impak het op die nakoming van antiretrovirale behandeling deur mense wat met MIV leef en om voorts uitdagings te ondersoek wat hulle met betrekking tot nakoming ervaar. Die hoofokus van hierdie ondersoek hou met die volgende vier temas verband.

(i) Om demografiese faktore soos ouderdom, geslag en sosio-ekonomiese faktore en die invloed daarvan op of bydrae tot nakoming te ondersoek met betrekking tot die invloed van kulturele en gesondheidsoortuigings in hierdie verband. (ii) Om die noodsaaklikheid van berading te bepaal en om kritieke uitdagings te ondersoek wat oorweeg moet word. (iii) Om die aard van ontvangs (negatief of positief) wat pasiënte in hierdie plaaslike gesondheidsfasiliteit ontvang, te ondersoek, met inbegrip van die aard van waargenome vriendelikheid van die jeug, aangesien dit 'n afskrikmiddel vir vertroulikheid met betrekking tot verwysings kan wees. (iv) Om waargenome verhoudings tussen gesondheidsorgverskaffers en pasiënte deur pasiënte met betrekking tot ondersteuningstelsels, verwysingstelsels en die voorkoming van stigma en diskriminasie te bepaal.

Hierdie studie bestaan uit 'n literatuurstudie oor nakoming in die internasionale asook Suid-Afrikaanse konteks, met 'n oorsig van die uitdagings wat deur talle Suid-Afrikaners en mense wat in hierdie land woon, ervaar word. Die studie is by 'n regeringsfasiliteit, Valsbaai Hospitaal, in 'n gesondheidsorgsektor in die Wes-Kaap uitgevoer deur een fokusgroepbespreking en tien semigestruktureerde onderhoude met pasiënte. Die bevindings van die studie toon dat stigma en diskriminasie die grootste oorsake van swak nakoming van antiretrovirale behandeling is, met inbegrip van maatskaplike probleme wat ervaar word deur mense wat met vigs leef. Ondersteunings- en beradingsprogramme wat by Valsbaai Hospitaal gebied word, is beduidend, maar bied nie noodwendig hulp aan mense wat met vigs leef wat ander uitdagings waarvoor hulle te staan kom, betref nie. Die studie toon ook die belang van gesondheidsopvoeding en dat goeie verhoudings met pasiënte 'n positiewe uitwerking op nakoming het en die kanse op beter gesondheid verhoog.

ACRONYMS

| | |
|--------|--|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Antiretroviral Treatment |
| ARV | Antiretroviral |
| DoH | Department of Health |
| FBH | False Bay Hospital |
| HAART | Highly Active Antiretroviral Treatment |
| HCP | Health Care Professionals |
| HIV | Human Immunodeficiency |
| HSRC | Human Science Research Council |
| MRC | Medical Research Council |
| PLWA | People (living) With AIDS |
| SA | South Africa |
| STI | Sexually Transmitted Infection |
| UNAIDS | United Nations Joint Programme on HIV/AIDS |
| WDOH | Western Cape Department of Health |
| WHO | World Health Organisation |

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CHAPTER 1: INTRODUCTION

Background information

A range of issues that characterised the epidemic for decades, and not just in the last decade, are still not resolved, and renewed vigour and determination is required to confront these challenges in South Africa. Some of these issues relate to “adherence to Anti retro-viral treatment”. It is also important to note that HIV/AIDS has succeeded in joining people around the world in a common consciousness about its threats and implications. Barnett & Whiteside (2002) note that HIV is the only disease to have a dedicated United Nations organisation- UNAIDS, that is charged with a single aim of confronting this pandemic.

In reality Human Immunodeficiency Virus (HIV) is incurable; no treatment can eradicate the virus from the human body. By far it is not a lethal disease by itself, but if untreated the virus can gradually weakens the immune system until it is no longer functional. HIV antiretroviral therapy (ART) can suppress the virus and delay the onset Acquired Immune Deficiency Syndrome (AIDS) for many years WHO, (2003).

In practice, adherence has taken on a range of definitions and interpretations, whereby WHO, (2003) defined adherence as the extent to which a person’s behaviour in terms of taking medications, following a diet and executing lifestyle changes, follows agreed recommendations from health care providers, and therefore dose adherence refers to the number and proportion of doses taken; schedule adherence refers to adherence to doses taken on time; and dietary adherence refers to doses taken correctly with food (Schonnesson et al 2006).

Frederick M. Hecht, MD argues that assessing patient adherence to HIV treatments is a key means to enhance patient understanding of the medication regimen, to identify potential obstacles to taking medications as prescribed, and ultimately to prevent virologic breakthrough. Querying patients about their adherence should always include using well-chosen words; it is the most important technique for clinical practice, including asking specific, non-judgmental questions can assist to maximize our opportunity to get information helpful in enhancing adherence to treatment.

Holzemer et al (1999) argues that the measurement of medication adherence is a difficult endeavour both in clinical care and research settings, and that there is no gold standard measure of adherence. Quantifying the levels and types of medication adherence involved patient care has been the focus of many studies resulting in the identification of multiple direct and indirect measures. Given the significance of viewing medication initiation and continuation as a process involving stages of change, measurement tools have been developed to attempt 'matching' communication strategies in readiness for treatment.

They further demonstrate that there are a variety of factors impacting a patient's ability to comply with a prescribed treatment regimen and are apparent at the patient, provider and treatment level. Together with the characteristics of HIV disease and therapies, these factors make adherence to treatment difficult. To assess or improve treatment adherence, the potential impacts of these factors must be considered. Based on prior theory, Icovics and Meisler (1997) outlined a multi-variable framework for clinical HIV/AIDS research and care to organize the factors that impact medication adherence.

South Africa is faced by a crisis when it comes to the effects of HIV/AIDS, not only because the virus mostly attacks those who are at the active reproductive stage of life, but because these are the people who are supposed to set out direction about the future of the country and yet they tend to die young.

Due to the severity of the pandemic and the massive damage it caused to the world and particularly to our country, South Africa was forced to conduct research programmes that will assist in finding causes and the precipitating factors and ways to mitigate the impact and the spread of the virus. Only a few large-scale population-based studies have been carried out in South Africa to explore human behaviour and social determinants, including a study conducted in 2002 by the Human Science Research Council (HSRC) in collaboration with the Medical Research Council (MRC) and the Centre for AIDS Development Research and Evaluation on national prevalence, behavioural risks and mass media. The project was population based; community based and international studies of behavioural risks were included with the HIV/AIDS mass media and communication environment in SA.

The Department of Health, (1998), acknowledged that in order to get a deeper understanding of HIV/AIDS, UNAIDS/WHO recommended the establishment of the second-generation

surveillance systems. The approach should combine behaviour, adherence, compliance and the HIV prevalence surveys. Taking into consideration the increased access to antiretroviral treatment in SA more especially in public health sectors we also need to consider in factors impacting on non-adherence in order to formulate appropriate strategies and interventions to manage and improve the situation.

Although medical research is focusing on ways to simplify medication dosages (e.g., developing drugs with fewer side effects, combining two drugs in a single capsule, developing longer lasting drugs, developing drugs with no adverse interactions with food or other drugs), it is clear that HIV-infected patients will continue to be faced with a significant medication adherence challenge. Interventions to assist patient adherence are needed. Even interventions that only increase adherence levels moderately could have important clinical significance for patients. For example, one study showed that a decrease of 10% in adherence was associated with a doubling of HIV RNA level, suggesting that small differences in adherence may result in major differences in virological control (Bangsberg et al., 2000).

Research problem and operationalization of the problem.

Why are patients on antiretroviral treatment not adhering to treatment at False Bay Hospital?

The principal focus of this investigation relates to three themes: To determine personal, community, structural and medical factors contributing to non-adherence including recommendations to the improvement on adherence and better use and effectiveness of HAART. The objectives of this research paper are to:

- To evaluate demographic factors such as age, gender, and socio-economic factors in contributing to adherence.
- Assess cultural aspects of the patient's health beliefs and life goals that may play a role as important influential factors in the context of treatment adherence.
- Establish the significance of counselling and critical issues that needs to be reviewed, such as the patient needs and challenges.
- The nature of the reception (negative or positive) that patients receive in local health facilities.
- This refers to the perceived youth friendliness of the local clinics as that may act as a deterrent for confidentiality with regard to referrals.

- To determine the experiences of patients when visiting the health care facility. This explores the effectiveness of internal referral system and the support given to people living with HIV and AIDS.

Hypothesis

A hypothesis is an expectation about a nature of things derived from a theory. It is further a statement of something that should be observed in the real world if the theory is correct, in addition it is essentially a statement that postulates the correlation or a certain relationship between two or more variables (Babbie & Mouton, 2011).

According to Christensen (2004) the formulation of the hypothesis logically follows the statement of the problem, as it is in this study, because we cannot state the hypothesis without having a problem. In the context of this study, the hypothesis represents predictions made on the relation that exists between two variables which is the problem and the solution. The hypothesis of this study was that stigma and discrimination is a triggering factor to non-adherence.

CHAPTER 2: LITERATURE REVIEW`

Key issues and trends in regard to adherence to HAART

UNAIDS (2007) Practical Guidelines for Intensifying HIV Prevention, outlines the importance of innovative and effective programmes in the fight against HIV/AIDS and the primary focus being young people. We should remember that clinicians do not always address secondary HIV transmission-risk reduction and related challenges (Cohen et al., 2002) with HIV- infected patients, though guidelines have been published and meta- analyses have shown that behavioural interventions can reduce the spread of HIV and promote adherence to ART (Murphy et al., 2002). In addition, on-going antiretroviral therapy (ART) adherence support is necessary for people living with HIV, especially in settings where second-line regimens are significantly more expensive.

Even after primary care and management of HIV and AIDS has been developed, there still remain significant obstacles to the effective use of antiretroviral treatment of which adherence is the most important element. Adherence to medications has generated substantial amount of academic interest for both medical and social science researchers over the past few decades. The growth of interest in this topic has been seen in over 4, 000 articles on the topic listed on Medline alone by 1990 (Donovan and Blake, (1992). This enormous interest can be attributed to the fact that a large number of treatment methods are self-administered by patients outside the clinical setting including ART. Patient adherence to Antiretroviral Treatment (ART) is an issue that is growing in prominence and generating a burgeoning interest with ART roll-out in South Africa.

Due to the observed rate and trend in the HIV and AIDS infection, this has brought more focus to young and middle age groups to the centre of the global AIDS epidemic of the 1.7 billion young people worldwide, 5.4 million are estimated to be living with HIV, UNAIDS (2007). About 40 per cent of new HIV infections are among young people. This age group also has the highest rates (over 500,000 infections daily, worldwide) of sexually transmitted infections excluding HIV/AIDS. Young people are particularly vulnerable to HIV infection because of social, political, cultural, biological, and economic reasons. Whatever their circumstances are, in order to protect themselves against HIV, young people need: Information, skills, youth-friendly health services and safe and supportive environment in order to promote and strengthen adherence to ART. Results show that not adhering to

treatment regimens is so wide spread that no combination of socio-demographic variables is reliably predictive of patients not following doctor's orders.

In the absence of a cure, ART is the only available option that offers the possibility of dramatically reducing HIV/AIDS-related morbidity and mortality, while improving the status of people living with AIDS (hereafter referred to as "PLWA"). However, successful administration of this treatment depends on sustained and strict adherence to the prescribed regimen (Dorrington et al 2006).

A study conducted by the department of psychology, Stellenbosch University, demonstrates that adherence plays an important role in determining quality of life, in either positive or negative ways. As social and behavioural factors affect adherent behaviour, these variables are likely to exert important influences on health care utilisation and therefore on health outcomes of persons living with HIV. Adherence may be operationalized in various ways. In achieving optimal results from ART, all of these dimensions of adherence are required. Non-adherence to ART may thus take various forms, such as not taking the medication at all, taking the medication at the wrong time, taking the wrong dose due to misunderstanding treatment directions, or prematurely terminating the medication without consulting the health provider (Haberer et al 2012).

Murphy et al. (2002) argues that although medical research is focusing on ways to simplify medication dosages (e.g., developing drugs with fewer side effects, combining two drugs in a single capsule, developing longer lasting drugs, developing drugs with no adverse interactions with food or other drugs), it is clear that HIV-infected patients will continue to be faced with a significant medication adherence challenges. Interventions to assist patient adherence are needed. Even interventions that only increase adherence levels moderately could have important clinical significance for patients. For example, one study showed that a decrease of 10% in adherence was associated with a doubling of HIV RNA level, suggesting that small differences in adherence may result in major differences in biological control (Haberer et al., 2012).

According to Ncama, et al. (2008). Prevalence is highest among pregnant women at 40.2% (South African Department of Health, 2007). In the age group of women 15–24 years of age, there are more than four infected young women for every infected young man, representing

the higher risk of women in part related to societal disempowerment and later In 2006, estimates indicated that over 700,000 individuals met the criteria for antiretroviral therapy (ART) while only 225,000 were enrolled in ART programs HIV disease is rapidly becoming the leading cause of morbidity and mortality in South Africa with co-morbid infection with TB also a leading cause of death, particularly in the KwaZulu-Natal province. Furthermore there is a need for a supportive social environment, it is critical for those infected and affected with HIV/AIDS. In KwaZulu-Natal, in South Africa, antiretroviral therapy is available to some HIV-positive individuals. Antiretroviral adherence is an important issue for limiting HIV infection. Adherence to therapy may be linked to social support, particularly amidst the stigma prevalent in HIV. Objective: The purpose of this study was to examine characteristics related to social support and antiretroviral medication adherence.

In many parts of the world, persons living with HIV (PLWA) who receive treatment and “optimal care” are living longer and healthier lives (UNAIDS, 2008a), more especially for most individuals living in developed countries and is beginning to be true for some who are living in developing countries as well (UNAIDS, 2008a). However, the ability to access the resources and services required to achieve longer life is not enjoyed by all PLWA. Achieving a longer life for all individuals is a challenge for developed as well as for developing countries. For many vulnerable PLWA, social contexts are constructed, whereby they are marginalized and shut out from the opportunities that are enjoyed by other members of a civil society (Burris et al., 2004)

Challenges experienced by people living with HIV and AIDS in regard to adherence to HAART

Development and research studies have shown that people who are infected with human immunodeficiency virus (HIV) are living longer and healthier lives as a result of better medical care, as there are major advances and improvements in antiretroviral therapy and the management of the epidemic, including prophylaxis of some of the initially fatal complications. However, many continue to experience distress from symptoms such as pain, fatigue, insomnia, anxiety, and depression and many more of the side effect of HAART; where by some people living with HIV are also at a greater risk for comorbid psychiatric disorders because of the high prevalence of drug dependence.

HIV and AIDS have a potential to challenge people in various ways and adherence to the complex regimen for HIV treatment is one of the core challenges. As AIDS continues to be the leading cause of death in the Sub Saharan-Africa among ages 18–44 years, heterosexual transmission of HIV especially from men to women is increasing. It has been discovered that with early recognition and treatment of problems such as distress, anxiety, depression, and other psychiatric symptoms in HIV positive persons can improve care, increase adherence, and decrease the transmission of HIV (Cohen, et al. (2002).

There is also a concept of stigma that is always attached to HIV as it relates to social identity, it was first introduced by Erving Goffman in 1963. In his highly influential book, *Stigma* has been defined as “an attribute that is deeply discrediting” He further identifies three different types of stigma: (a) abominations of the body, (b) blemishes of individual character, and (c) tribal stigma of race, nation, and religion. He recognized that the issue does not exist separate from the context in which it resides, immediately noting that the term requires a “language of relationships, not attributes” HIV remained shrouded in mystery for several years after its initial identification, contributing to the stigma of those who were infected and those whose lifestyle indicated they might be at risk for infection (Colbert, et al. (2010).

According to Colbert, et al. (2010), disclosure concerns refer to whether individuals tell others about their diagnosis. Negative self-image is whether having HIV makes one feel badly about oneself such as shame or feeling “unclean.” Concern over public attitudes towards PLWH includes discrimination and the reactions of the public to PLWH. Haberer et.al (2012), argues that there is a number of other factors related and contributing to adherence such as family structure, socioeconomic status, disclosure, hospitalization and medication routine and/or regimen have all been significantly associated with ART adherence.

Most studies have relied on caregiver-report although some studies have used objective measures such as pill counts, pharmacy records, therapeutic drug monitoring as well as directly observed therapy and electronic monitoring. Because it can be a challenge for both HCPs and patients to openly discuss about some of the things personal such as sexual behaviours, substance abuse, disability, and death Epstein et al., (1998), providers must be aware and sensitive to how they respond during interactions with patients (Bodelos, et al. (2011). People living with HIV/AIDS (PLWA) without general literacy challenges may

struggle to fully comprehend the technical and domain-specific vocabulary often used by health professionals to explain concepts, (Kessler (2011)).

Colbert, et al. (2010) States that stigma remains a salient issue for people living with HIV (PLWH) in the United States and in all other African countries. Although there is now greater understanding about the disease and its transmission than in past decades, efforts to reduce stigma and its repercussions for PLWH have shown only moderate success. HIV-related stigma is associated with negative self-perceptions, lower rates of HIV-status disclosure (Cohen et al, (2002)). Stigma is also a public health issue because of its social nature of transmission and therefore as part of the interventions to improve and eradicate the problem there has been programmes targeted at alleviating stigma have been implemented to help and improve live of people affected and infected with HIV.

Haberer et al (2012) argues that alcohol use is also a common cause of poor adherence among adults taking ART and these effect likely transfers to the child's adherence if a parent or guardian is looking after an infected child. Additionally, the protective effect of increasing household assets against adherence interruptions may reflect the caregivers' ability to overcome structural challenges in obtaining medications. According to Johnson, et al. (2010), another factor contributing to medication adherence is health literacy, the ability to understand and use health information to make important decisions affecting one's health. Previous studies have shown that limited-literacy patients have difficulty correctly identifying medicines and understanding how to take medicine sometimes they are reluctant to ask providers questions, possibly because they are ashamed to admit they do not understand.

Henderson et al (2011), states that barriers to adherence are very complex and may arise from a combination of factors. A review of determinants of adherence to ART suggested that length of time on ART treatment, high baseline viral load and resistance patterns, psychological comorbidities, increased pill burden, and higher dosing frequency increased the odds of non-adherence. As such, clinical interventions are typically individualized based on patient-specific parameters in an effort to remedy underlying causes of non-adherence. Although studies consistently demonstrate the importance of good ART adherence for the optimal treatment of HIV, the precise threshold for "good" adherence with contemporary ART regimens has not been definitively established.

A study conducted by Paterson et al. (2010) Demonstrated that 95% adherence or more is needed in order to minimize the risk of virologic failure. However, if a patient perceives discrimination in the health care setting, this may negatively impact the relationship with his or her HCP. Schuster et al. (2005) reported that 26% of a nationally representative sample of HIV patients perceived discrimination in the health care setting. In addition, stigma in general as one of the ethnographic studies gave additional insight into how stigma affects women: It increases reluctance to seek health care, creates barriers to medication adherence, and limits social interaction and social support (Carr & Gramling, (2000).

CHAPTER 3: RESEARCH DESIGN

Research methodology

A qualitative research method was used in the study. Christensen (2004) defines qualitative research design as interpretive, multi-method approach that investigates people in their natural environment. A case study, as part of qualitative research, was used to complement the survey technique for validity checking (Morgan, 1998). A case study refers to an intensive analysis of an organization (False Bay health care Centre) based on information obtained from a variety of sources, such as semi-structured interviews and in focus groups in the context of this study (Christensen, 2004).

Sampling Design

In testing the hypothesis that there is poor education on ART and referral system, systematic random sampling was used. Random selection of eight to fifteen patients for both semi structured interviews as well as the focus group method was conducted in the hospital. The targeted age group of the participants was between the ages of 18 to 45 years of patients who have been on the anti-retroviral therapy for at least a period of a year and more.

Data collection

Permission to conduct the study was approved by False Bay Hospital and from the Western Cape Department of Health. Data collection commenced under the basis of the institutional permission given on the 10th of December to the 4th of January 2013. Date and time of the interviews was arranged with the sister facilitating the ARV clinic and ward sisters, scheduled to suit and not to interfere with their work or to inconvenience the patients. The informed consent process was done by the researcher giving a verbal explanation to each potential participant about the nature of the study, the process including the written consent, duration of the session and what was expected, potential benefits and risks involved. All participants were made aware of their right to participate voluntarily and that they can withdraw at any time if they felt a need not to continue participating.

Notably, with regard to the methodology, semi-structured interviews and the focus group interviews were conducted in a spare consulting room at False Bay Hospital using. The interview and focus group questions for patients covered the following topics:

- The perceived effectiveness of the hospitals internal referral systems from department to department according to patient's needs;
- Challenges and the perceived impact of the antiretroviral therapy. The counselling received by patients to identify their needs and refer them accordingly;
- Follow up done regarding the referrals done to further assist the patient and making sure that needs are met;
- Local health facility's environment with regard to youth friendliness; and
- Experiences of patients with regards to medical assistance and referrals.

The aim of using this research methodology was to investigate and discuss the experiences of patients in regard to recognition and referral, and the actual action of referral taking into account the other variables that could correlate with referrals. Here, the descriptive research can provide input with regard to the effectiveness of community mapping exercises as well as variables such as; the nature of support provided to patients, youth friendliness of the support centers, informal charts including referrals, qualitative inputs with regard to the issues they handle from patients and the attitudes of the multi-disciplinary team with regard to the internal hospital referral systems.

Interviews

Notably, semi-structured interviews are used in this evaluation because they are well suited for the exploration of the perceptions and opinions of respondents regarding complex and sometimes sensitive issues, and enable probing for more information and clarification of answers (Barribal and While, 1994). Semi-structured interviews allow all participants to be asked the same questions within a flexible framework (Dearnley, 2000; as cited in Polit and Beck 2006). In the context of this evaluation, participants were encouraged to talk about their experiences largely through open-ended questions.

The open nature of some of the questions aimed to encourage depth and vitality, and to allow new concepts to emerge. For example, the interview schedule for this study consists of a question about the challenges that the participants are to identify regarding the referral system; this question may allow the researcher to probe further as the participants may identify different challenges; and thus the subsequent follow-question may also differ

depending on what the respondents identified as challenges. The use of probes is an invaluable tool for ensuring reliability of the data as it:

- allows for the clarification of interesting and relevant issues raised by the respondents (Hutchinson and Skodal-Wilson, 1992);
- can elicit valuable and complete information (Gordon, 1975);
- enables the interviewer to explore and clarify inconsistencies with respondents' accounts (Barribal and While, 1994);
- can help respondents recall information (Smith, 1992); and
- Contributes to ensuring validity of the study; Hussey and Hussey (1997) argue that validity can be increased by the collection of data that is rich in explanation and analysis.

Semi-structured interviews give effect to the fact that respondents do not necessarily share a common vocabulary (Barribal and While, 1994); the opportunities to change the words and not meaning provided by semi-structured interview schedule acknowledges that not every word has the same meaning to every respondent and not every respondent uses the same vocabulary (Treece and Treece, 1986). Clearly, in this type of interview, validity and reliability depend, not upon the repeated use of the same words in each question, but upon conveying equivalence of meaning (Denzin, 1989). It is this equivalence of meaning that helps to standardize the semi-structured interview and facilitate comparability (Barribal and While, 1994). Furthermore, Seidman (1937) argues that the use of semi-structured interviews affirms the significance of the adaptability of the instrument (the human interviewer) as opposed the rigid instrument in quantitative research questionnaires or in highly structured interviews. In particular, semi structured interview schedules provided an opportunity for the interviewer to be flexible and reduced the risk of socially desirable answers (Lincoln and Cuba, 1985; as cited by Seidman, 1937), provided that the evaluator is well trained.

The researcher took care to ensure that the greatest critique often cited about semi-structured interviews is indeed not manifested in this study. As Christensen (2004) puts it, semi-structured interviews have the advantage of allowing the interviewer to clear-up any ambiguities in the question asked or to probe for further clarification if the interviewee provides an inadequate answer, but all this depends on the interview skills of the researcher. Therefore, the researcher ensured that appropriate follow up questions / probes were used to develop a thick description as shown in the discussions of the findings.

Focus Group

The focus group method was utilized to complement the methodology technique for validity checking, (Morgan, 1988). Powel et al, (1996) defines a focus group as a group of individuals selected and assembled by researchers to discuss and comment on, from personal experiences on the topic that is the subject of research. The recommended number of people per focus group is usually six to ten (Maclintosh 1993), but some researchers have used up to fifteen people (Goss and Leinbach 1996) or as few as four (Kitzinger 1995).

A focus group was used to gain more detailed information on the research question. The benefit for using the focus group is that patients can become a form of change (Race et al 1994), both during the focus group meeting itself and afterwards. For example, in research conducted by Goss and Leinbach (1996), the participants in the research experienced a sense of emancipation through speaking in public and by developing reciprocal relationships with the researchers. If patients with all stakeholders in hospital, trust develops and they may explore solutions together with regard to referring to their patients to community support structures as a unit (Kitzinger 1995), rather than as individuals. Furthermore they are useful in exploring ideas and concepts, provide a window into the participant's thinking and allow probing and also allow a quick turnaround (Christensen, 2011). Focus groups will also provide an ideal opportunity to discover how and why the multi-disciplinary team interacts with their patients and community structures. "It is only a story not worth telling, due to its inherent simplicity, that numbers will suffice" (Patton 2002:151). This qualitative research design has the potential to incorporate phenomenology as a strategy of investigation.

This evaluation will specifically use semi-structure interview schedule as a mechanism to collect data from the participants, albeit the fact that there are types of interviews. This type of interview is inherently more flexible than the structured type and allows the evaluator to elicit the personal and social context of beliefs and feelings (CREST teaching material, 2011). Babbie and Mouton (2011) further argues that semi-structured interviews differ from most other types of interviews in that they are open interviews which allow the object of study to speak for him/her rather than to provide a respondent with a battery of the researcher's predetermined hypothesis-based questions

This particular investigation seeks to obtain a better understanding of the issues that affect people on ART, that can be the support they need and with regard to the effectiveness of our health care facilities, as well as in variables such as challenges or barriers to adherence.

Ethical considerations

Ethical considerations for both the interviews and focus groups are the same as for other methods of social based research (Homan, 1991). Particularly ethical issue need to be considered in the context of this study as it is handling of sensitive issue; confidentiality was included given that there was more than one participant. At the outset, participants needed to be aware that they did not need to mention names as referred to during the sessions.

Participants were encouraged to keep confidential the scenarios they heard during the meeting and were given the assurance that the data from the group would remain anonymous, no names would be used and the report findings would not be used in a way that reveals the participants. Debriefing sessions were also conducted. Consent forms were given to the participants in line with the policies and procedures in the department of health. The information were stored safely during the process.

The research process was commenced after permission was given by the ethics committee and the Western Cape Department of Health approval for the go ahead. The period for data collection was covered over a period of a month including the analysis of the findings and recommendations were done over that period.

Data analysis

According to Creswell (1994), data analysis involves reducing and interpreting data; the evaluator reviewed voluminous data and reduced it to specific themes to interpret the information. The notes collected during interviews included the researcher notes and debriefing notes. In particular, interview data was loaded into Atlas.ti and coded. Atlas.ti refers to software for qualitative data analysis. Carefully selected quotes were presented in various Networks as part of data analysis.

Bruce Berg (1989; cited in Babbie and Mouton, 2011) places code development in the content of grounded theory and likens it to solving a puzzle:

“Coding and other fundamental procedures associated with grounded theory are certainly hard work and must be taken seriously, but just as many as people enjoy finishing a complicated jigsaw puzzle, many researchers find great satisfaction in coding and analysis. As researchers ...begin to see the puzzle pieces come together to form a more complete picture, the process can be downright thrilling.”

As noted by Babbie and Mouton (2011) throughout this activity (i.e. coding), the researcher ensured that the operational definition of any variable consisted of the attributes included in it. In the context of this study, the themes identified and discussed included: referral system, log books and statistics, counselling, challenges and support service.

Limitations of the study

Some of the challenges in methodological research in this scenario is to rely on self-reported changes in attitudes, behaviour and experiences. According to Karim, (2008) patients are chosen for initiation of therapy on the basis of either the presence of clinical symptoms and/or laboratory immunological parameters; even though treatment guidelines are followed there is still a possibility that a person may not be ready more especially pregnant woman. One of the issues is that there has not been an evaluation of the impact upon readiness of patients to initiate ART, as a matter of fact and mostly towards women it is not a matter of a choice as they would want to protect the unborn child.

Another difficulty concerns the uncertainty of attributing any change in knowledge or understanding and behaviour to the information and care given by the health care practitioners provided that patients are likely to be exposed to a range of other sources of information, not forgetting their traditions and beliefs.

CHAPTER 4: RESEARCH FINDINGS AND DISCUSSIONS OF FINDINGS

Findings

Finding presented below are based on three broad areas of the study and the study questions as follow, 1) Referral system, 2) Log books and statistics, 3) Counselling, challenges and support services.

Referral system: Patients appears to have different views about the referral system used, while others have an understand about how things are done in that way and they have seen the progress brought buy the system; on the other hand some feels that the system used is problematic to them.

Log books and statistics: There is a positive outcome about how the information is kept because patients feel that they do not struggle even when seen by different practitioners because the information with everything is always readily available in their files.

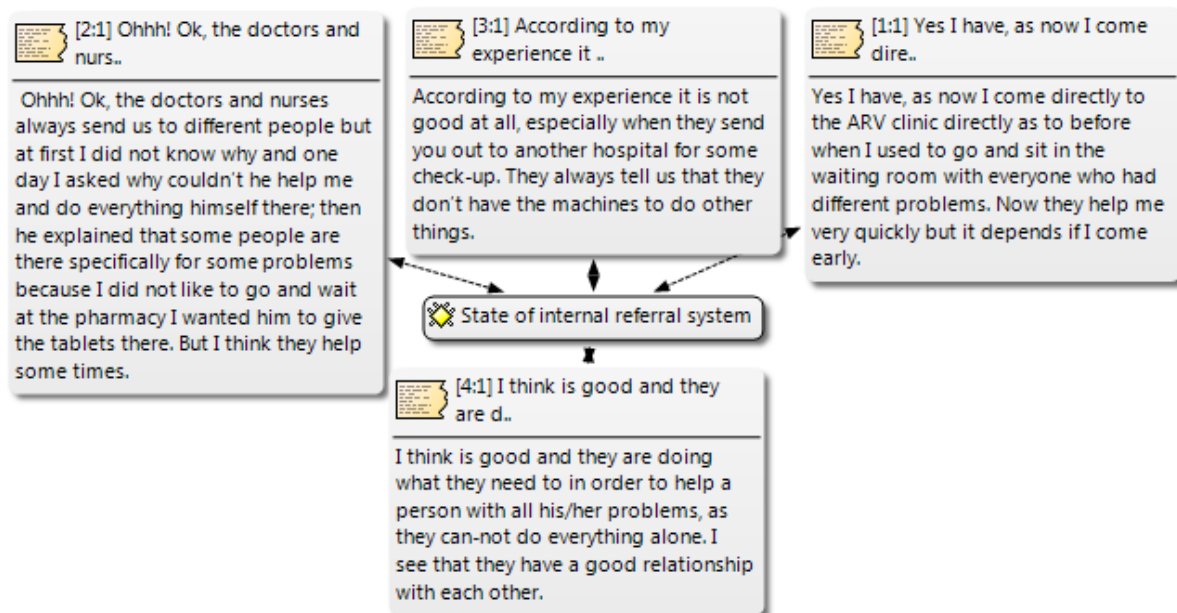
Counselling, challenges and support services: The burden and a challenge towards women once again came up, where you find that they are victims emotionally and in many other ways to their spouses. Some of the serious concerns in HIV and AIDS including our cultural diversity and how that affects our understanding to the management of the epidemic and these were noted as some patients mentioned it. In addition, stigma and discrimination was demonstrated by the majority of the participants as their most challenging issue , furthermore under all those challenges patients demonstrates appreciation in regard to assistance given to them and it makes a huge difference in their lives.

Discussion on Findings

REFERRAL SYSTEM

State of internal referral system: As depicted on network 1 below, the interview with patients revealed that patients have mixed experiences about the internal referral system. On the one hand, the referral system is regarded as not good due to the lack of availability of equipment, and the time taken - waiting period – prior to receiving treatment is too long while on the other hand the newly established ARV clinics seemed to have reduce the waiting period and the dedication of the nursing staff in “doing what they can do” appears to be strengthening the referral system. As noted by (Ncama et al (2008) in antiretroviral poor adherence can result to resistance problems therefore it of great importance to manage patients holistically and that includes involving different members of the multi-disciplinary team to succeed, to be able to support that South Africa requires a standardised and simple treatment regimen.

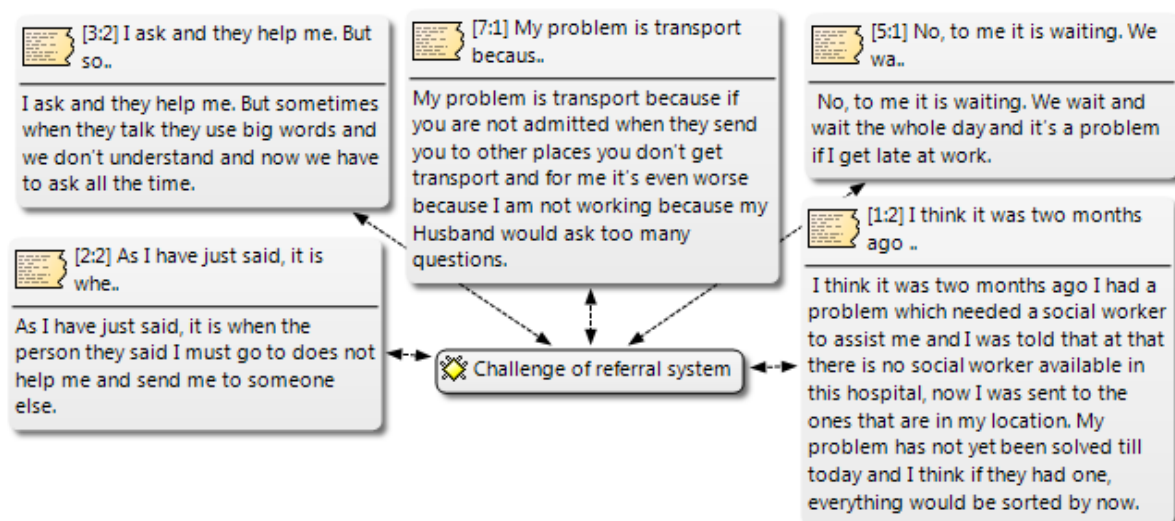
Network 1: State of internal referral system



Source: Interview transcripts

Challenge of referral system: As shown on the network 2 below, patients indicated different views on challenges they come across with the Hospitals referral system such as the language used by health professionals who appeared to be a barrier to better communication and it demonstrates confusion and difficulty in understanding. Furthermore, network 2 reveals that some view the system as failing as they are not assisted even when referred to certain departments, in addition there is a clear problem and financial constraints when it comes to transportation to those dedicated destinations. This demonstrates the need to manage the programme and expected challenges within a limited internal infrastructure, revised service delivery models and that requires a re-arrangement and the involvement of government and facility managers.

Network 2: Challenge of referral system



Source: Interview transcripts

The challenge in regard to transport referred to above was further enunciated by a focus group participant as presented below:

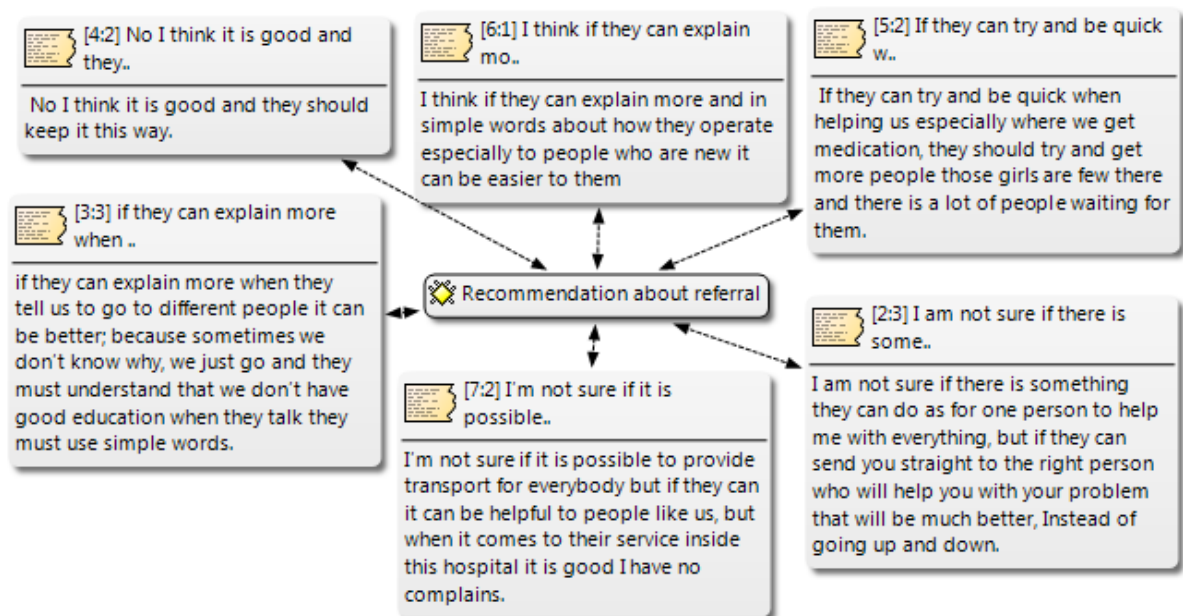
Codes: [FG: Referral system]

Yes I believe so, but in some problems they cannot help us here because there is no social worker then we have to be sent somewhere else and these places are far especially when you don't work and with no money for transport because I don't work.

Source: Focus group Respondent

Recommendations about referral: As reflected in network 3 below, the interview with patients on what they recommend demonstrated different views, some feel that they are given the best service as to the way it is supposed to be and recommend that it should continue the way it is; on the other hand some suggests that they should simplify the language to accommodate everyone; while others understands that some of their challenges solution cannot be resolved by the health providers as they are doing what they can to help them. It is indeed a challenge for the health sector and the hospital or clinic departments to meet everyone's needs and in a real world people understand that but at times they can be ignorant or expect more because they have no choice. Finding out about the communities concerns and challenges should be part of the programme in order to identify these problems and address them before they can affect the way people adhere on ART.

Network 3: Recommendations about referral

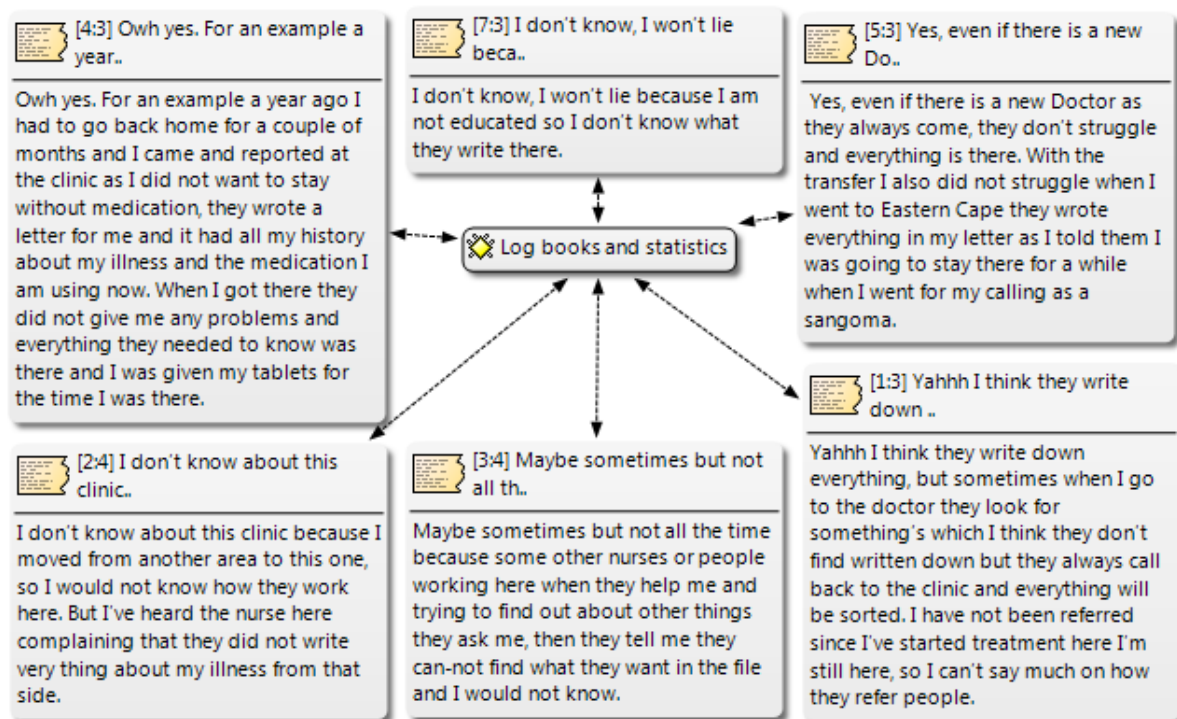


Source: Interview transcripts

LOGBOOKS AND STATISTICS

Logbooks and statistics: A reflection network no 4 below presents views of patients on how logbooks and statistics are kept at False Bay Hospital. It seems there is a common perception about their satisfaction on how records are kept. Some do not have an experience on matters concerning transfers, but their overall view shows confidence towards health care professionals and how their hard work that has helped them and brought change and a huge difference in their lives. The ability to access the resources and services required to achieve longer life is not enjoyed by all PLWA. Burris et al., (2004) argues that achieving a longer life for all individuals is a challenge for developed as well as for developing countries, for many vulnerable PLWA, social contexts are constructed, whereby they are marginalized and some are shut out from the opportunities that are enjoyed by other members of a civil society. Therefore proper care, records and follow ups is appreciated by these patients even though some of them have a low level of education but at the end of the day their needs are met.

Network 4: logbooks and statistics



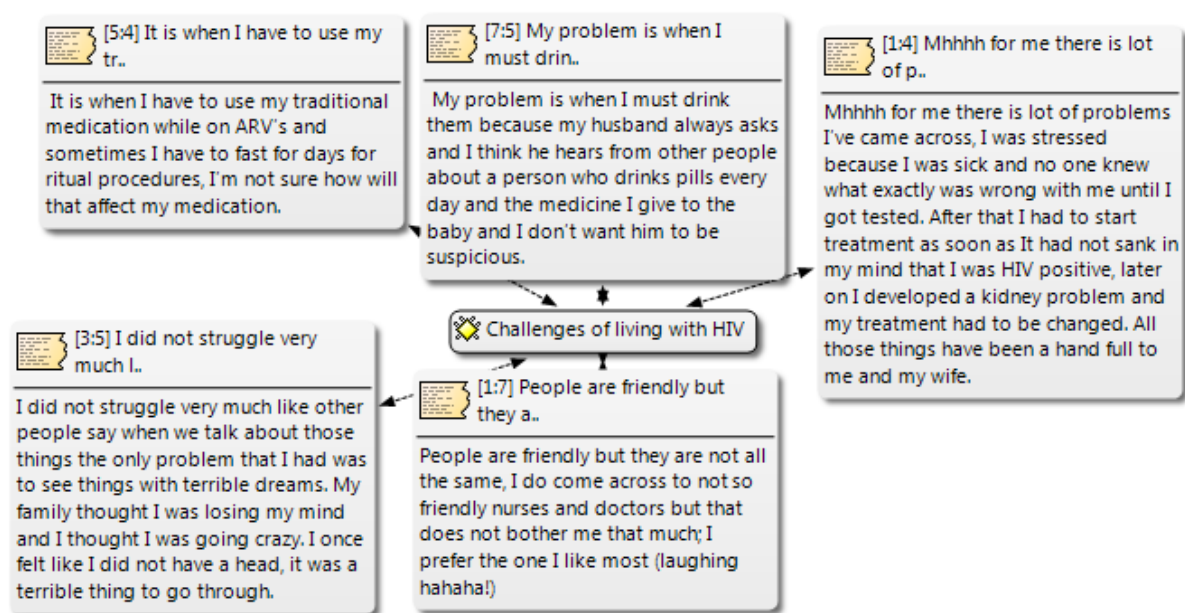
Source: Interview transcripts

COUNSELLING, CHALLENGES AND SUPPORT

Challenges of living with HIV: Network 5 (1) reflects the views and experiences of patient and their lives with HIV/AIDS, there seems to be a clash between HIV and different cultures as some things clash because people have their certain beliefs. At some point stress about this disease and challenges such as stigma and where people at some point have to hide everything, even to the closest family members has been noted as one of the major challenges, they had to compromise and make drastic changes .

Siegelt, K. (2004) argues that when dealing with serious challenges there has to be changes in order to cope and manage situation and these changes may also contribute to the greater use of problem-focused coping strategies by rendering patients more willing to acknowledge and attempt to address stressors associated with their disease. Yet, coping can play an important role in the understanding of psychological adjustment. According to Chesney et al (2000), training for health care providers to increase cultural competency and better understanding of different cultures and religion to work with transgender patients increase patient trust, and promote positive interactions between patients and providers may help to cultivate an atmosphere that is more conducive to fostering greater adherence self-efficacy and medication adherence among people living with HIV.

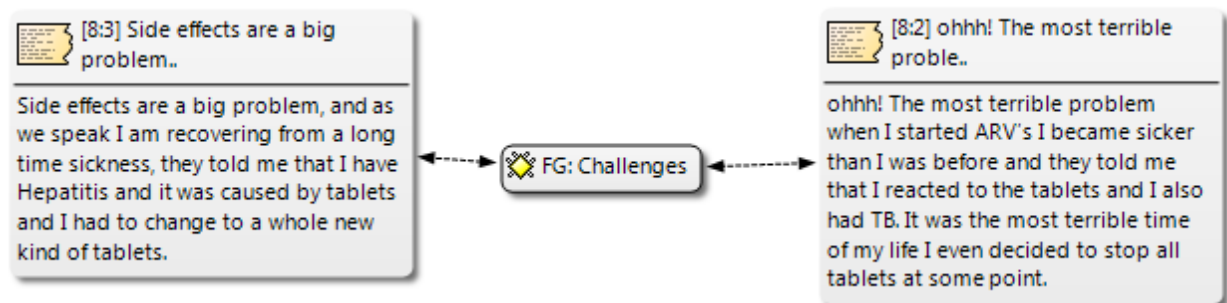
Network 5 (1): Challenges of living with HIV



Source: Interview transcripts

As noted by the participants in a focus group – Network 5 (2) - the challenge of side effects as a result of taking ART is pervasive. Indeed, Henderson et al (2011) points out that a study that was conducted in 2007 revealed that a fixed daily dose combination of tenofovir, emtricitabine, and efavirenz reduced the problems associated with side effects due to simpler daily dosing.

Network 5 (2): Challenges of living with HIV

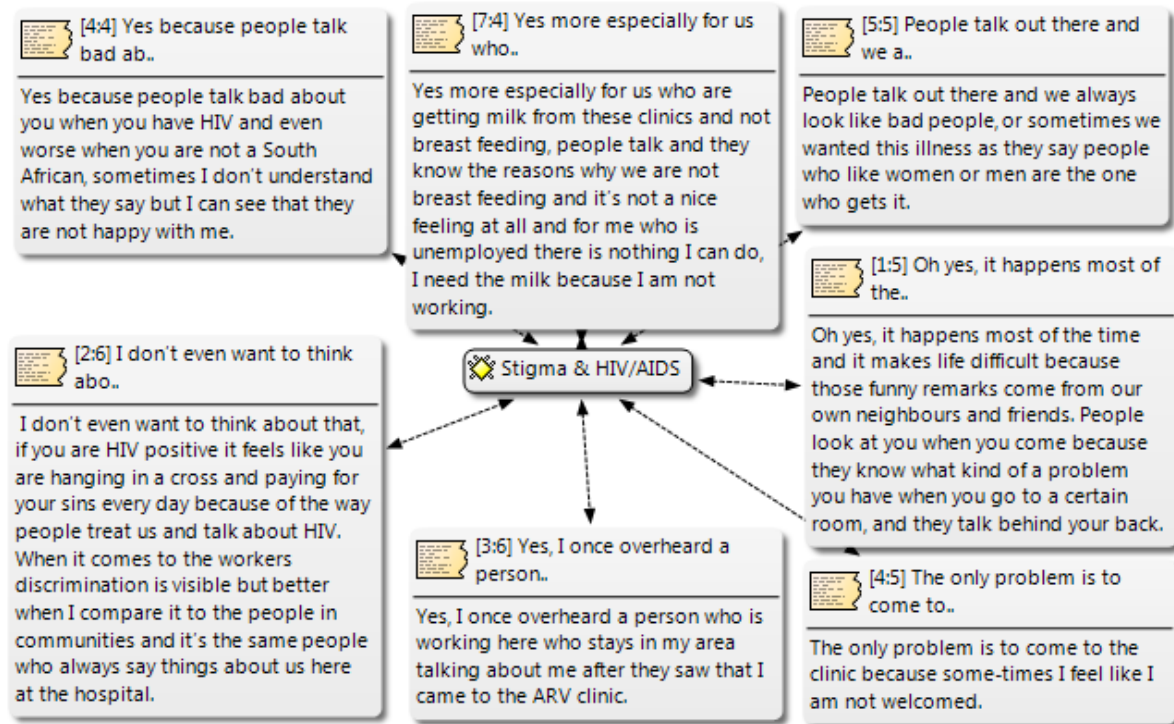


Source: Focus Group Transcript

Stigma & HIV/AIDS: Network no 6 below demonstrates to us one of the serious challenges PLWH undergo and a reflection of their views on how this affects them. South Africa is one of the most diverse countries and democratic, as a result to that it has become a home to many people of the neighbouring countries; it is clear that stigma and discrimination goes beyond our democracy. People seemed to have a mutual feeling on bad experiences which are mostly coming from our friends and families more than anywhere else, as a result stigma has been identified as a catalyst to the spread of HIV AND because people cannot talk openly because of judgement.

Despite advances in education and prevention efforts, a great deal of confusion persists about disease transmission within the homosexual population and the rest of the country, (Herek et al. 2005). The study showed that women, by virtue of being women, had several unique issues that potentially resulted in real and perceived stigma, including the ability to bear children, sexuality and presumed promiscuity.

Network 6: Stigma & HIV/AIDS

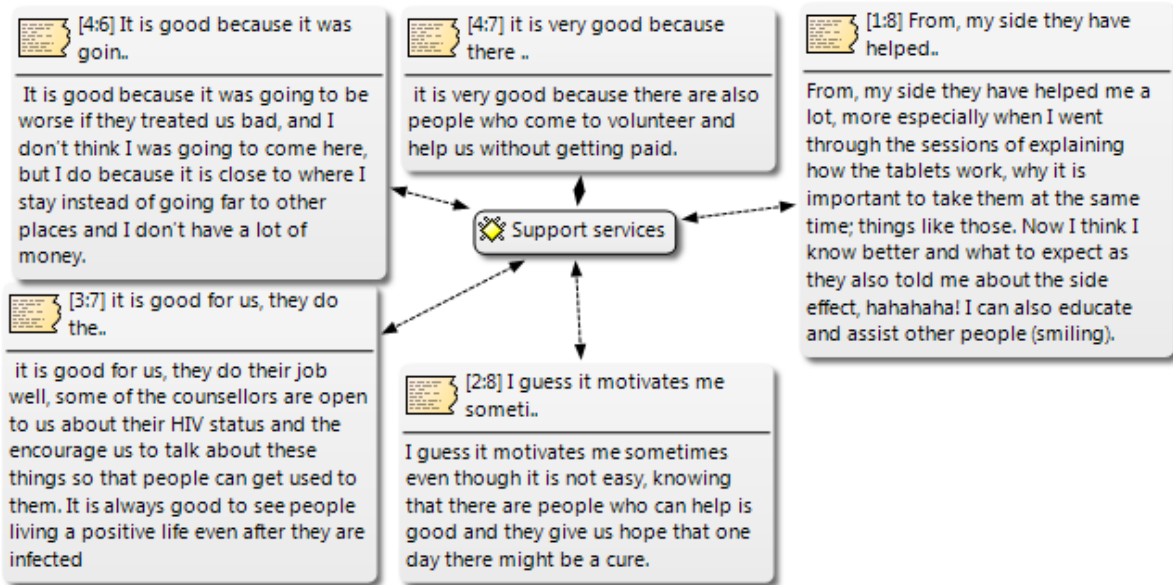


Source: Interview transcript.

Support services: The network below - 7 (1) and 7 (2) - presents the views of patients on support rendered by health providers. Some admire what has been done for them and they feel like they couldn't have made it without such help even on private personal challenges made by the disease; some acknowledge the difference it has made in educating about the disease and understanding it better; furthermore it gives hope and it is accessible to the nearer and poor community which cannot access private care.

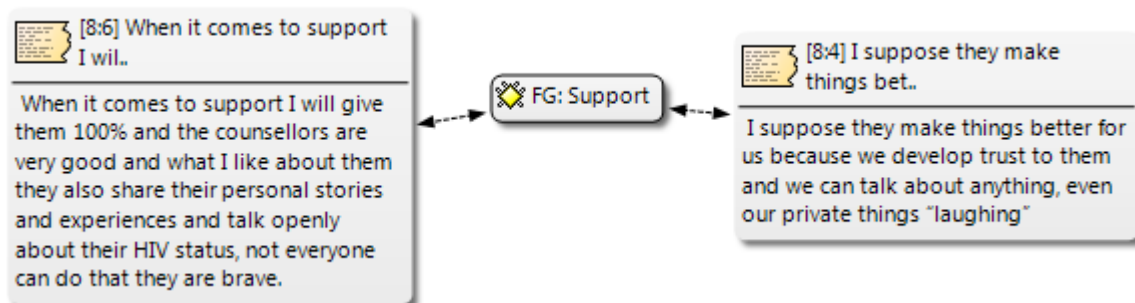
It can be challenging for patients who must take medication every day for an indefinite length of time. These circumstances, along with the negative side effects of ART regimens, contribute to the difficulty faced by patients trying to maintain optimal levels of adherence. Much research has focused on identifying methods to increase adherence and social support has been associated with greater treatment adherence in individuals infected with HIV and may be a key component of adherence interventions (Simoni, et. al, 2006).

Network 7 (1): Support services



Source: Interview transcripts

Network 7 (2): Support services



Source: Focus Group Transcript

Counselling recommendations: The quotation presented below reveals that a focus group participant suggested the need to increase the human resource capacity of the facility in order to meet the needs for patients. As shown below, the participants highlighted the following:

Codes: [FG: Recommendation]

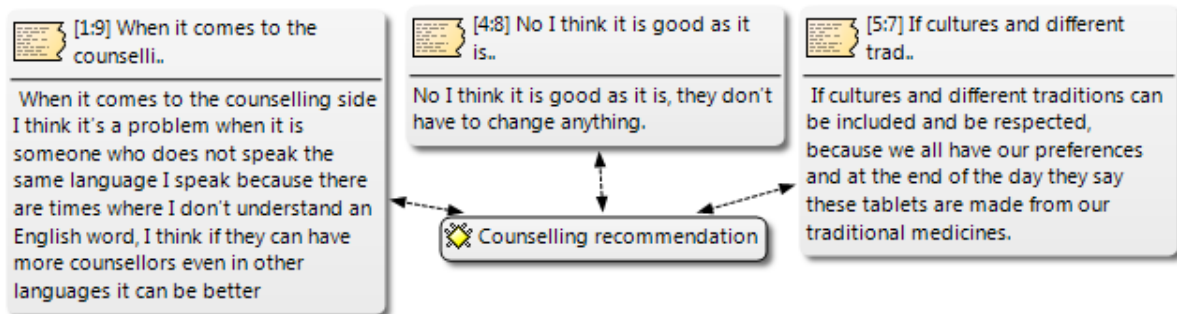
I would not change anything, or only to add more staff because they are few with many people to attend to.

Source: Focus Group Participant

As depicted in Network 8 people want to be helped in any possible way, but there are few challenges that seem to be disturbing the process. Due to their experiences some feel like the

language used restricts them in better understanding as we live in a very diverse country. In addition, our diversity includes our cultures and religions which also require an overview as differences can become barriers to better care and management.

Network 8: Counselling recommendations



Source: Interview transcripts

Recommendations

- Kessler, (2011) recommends that ART adherence knowledge is crucial in the management of the epidemic, there are number of ways that can be used in making sure that people have a better understanding especially with those who are illiterate. Knowledge measure may consist of vignettes created to assess participants' understanding of the importance of dose timing to avoid drug resistance and promote adherence.
- Facilities should developed various types of social support and emotional support (*having someone in your life who provides empathy, who cares about you, and whom you trust*), medical information support (*having someone to help you read written materials you get from a physician or hospital*), healthy reminder support (*having someone remind you to do activities to help you stay healthy, such as taking medicines*), and tangible support (*having someone help you with various tasks such as giving you information to help you understand a situation and helping with daily chores if you are sick*).
- Due to the outcomes of the study it is of great importance for health care providers to understand each other's differences and try to meet each other half way in sensitive issues of diversity in order to achieve better outcomes. Perceived social support refers

to the network of people and resources available to an individual specifically, social support refers to the system of family, friends, neighbours, and community members who are available to provide psychological, physical, and financial help (Cohen, 1985). Therefore in the development of programmes to mitigate the impact we need to support each other, which is mostly what we struggle with because of stigmatisation and discriminating one another.

- Colbert, et al. (2010) argues that in order to design effective interventions, it is first necessary to examine how these layered factors, including gender, differently affect the experience of stigmatization and which factors may predispose an individual to or protect an individual from the harmful effects of stigma. For example, male homosexuality and HIV have been inextricably linked throughout the course of the disease. Despite advances in education and prevention efforts, a great deal of confusion persists about disease transmission within the homosexual population.
- Patients who are willing to assist others should be granted an opportunity to share their experiences qualitatively with regard to their experiences before taking ART and during this process with newly diagnosed patients.
- Hospitals internal and external referral systems should be communicated with patient so that they are prepared to what to expect in-line with policy prescriptions.
- Several studies have demonstrated the association between low health literacy and lower educational attainment with poorer ART adhere. Effective pictorial communication tools may be particularly useful to improve understanding and subsequent ART adherence among such populations. Most of the time patients are not likely to disclose that they have difficulty understanding their medication instructions. Moreover, many pharmacists have large numbers of patients to serve and limited face-to-face time with patients. Therefore, expecting pharmacists to screen each patient for limited health literacy so they can then tailor counselling sessions to match the patient's needs may not be feasible. A better approach is for pharmacists to follow universal precautions and assume that every patient has limited health literacy, and

practice clear communication with all patients, not just those with limited health literacy

- For those with no trusted confidants, all other types of support could have minimal benefits because the people providing support are unaware of the patients' reading difficulties. These explanations are consistent with previous studies documenting that limited-literacy patients keep their reading difficulty as a secret from family and friends (Johnson, et al. (2010).

Conclusion

There has been a trend of findings that demonstrated a link between support and adherence concluding on the fact that additional support for the role of the caregiver in establishing routine medication taking, as well as patient-provider relationship remained an important predictor of HIV medication adherence, even when considering the impact of mental distress and substance abuse. However, it remains unclear how attitudes toward HCPs affect appointment attendance for HIV patients. The protective effect of caregiver use of ART suggests that caregivers taking ART themselves may have established effective means for adherence, which can then be passed on to the children. Because patients have frequent contact with medical staff for provision of standard HIV care, it is likely that the patient-provider relationship influences appointment attendance. Additional psychosocial factors have been consistently related to HIV adherence behaviours, including depression and level of social support.

Cohen, et al. (2002), suggests that younger patients and people that had not yet accepted their status are more likely to experience greater distress when compared with older patients and more likely to be distressed during the second or third decade of life when compared with patients who have been on HAART for longer periods and adapted a coping mechanism to most challenges. Furthermore younger patients may have received their diagnosis more recently than older patients, who may have had more years to adjust to and accept their HIV diagnosis.

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ANNEXTURE: INTERVIEW AND FOCUS GROUP SCHEDULES

Allow me to take this opportunity and welcome you and I wish to thank you for agreeing to spend an hour with me. The purpose of the session is to discuss your experiences in regard to taking the antiretroviral treatment as a person who is living with HIV and AIDS.

As per the form that you signed earlier, I wish to remind you that your participation is not about providing the correct or the wrong answer, but it requires your true reflection about your own personal experiences. The lessons from this study will be used in initiatives to improve the medical and support services provided to people living with HIV and AIDS.

This session will take about 40 minutes to an hour. Please be reminded that our discussion will not be shared with anyone (i.e will be kept confidential). You are allowed to raise questions with me during the session, and please remember that you have the right not to answer questions that you feel comfortable with.

The interview will be semi-structured, guided by the following kinds of questions:

Internal referral systems

- What is your view on the referral system used by the hospital?
- Have you been referred to the correct areas within the hospital and according to your needs?
- What challenges have you experienced in regard to referral?
- How do you think that the system should be improved? (If at all).

Log books and statistics

- Are records on your progress and clinical visits properly documented and recorded?
- Do you always get information about your attendance and medical treatment when needed? (For example, when applying to be transferred to other health institutions?)

Counseling and challenges and support services

- As a person who is on treatment, what kind of challenges do you experience (Probe for physical, psychological or medical challenges)?
- Have you experienced HIV/AIDS stigma and discrimination when visiting this health facility?

- Are there any problems that you encounter in taking antiretroviral treatment and how do you deal with those problems?
- Describe the nature of the relationship with this health care facility and the health providers in terms of support system. How does such a relationship impact you in receiving all the services?
- What are your views on the support and counseling system?
- What advice would you give to improve these services?

Your cooperation is greatly appreciated.